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**Analysis of the Population and Baseline Needs
Assessment for the Children with Disabilities
Coordinated Care Program at Naval Hospital,
Jacksonville, FL**

**A Graduate Management Project
Submitted to the Faculty of
Baylor University
in Partial Fulfillment of the
Requirements for the Degree
of
Master of Health Administration
by
Lieutenant James G. Diehl, MSC, USN
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ABSTRACT

This project provides a solid indication of the potential user population (ages 0 - 21) for services under the new Children with Disabilities Coordinated Care (CDCC) program. It further documents a basic needs assessment of specialized medical services needed by dependent children in the Naval Hospital Jacksonville (NHJAX) catchment area.

A detailed review of the literature clearly supports the need and benefits of such a program. A survey of families who have disabled children indicates that the majority of care is delivered in the civilian community external to Naval Hospital Jacksonville. Increased assistance in getting services in the naval hospital, help with getting services in the community, and access to more and better information about available services are some of the basic findings of the survey.

The findings contained in this project are immediately pertinent to the hospital task force that is developing the CDCC program. By using this information, we will be able to focus on the kinds of assistance that will make a significant impact for our beneficiaries. They have spoken, we must listen.

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This paper is dedicated to all of the special families in Jacksonville, who not only make the sacrifices of military life, but must do so with the additional challenge of caring for children who have special healthcare needs. I thank the 61 families who took time to talk with me and teach me what it is like to care for children under difficult circumstances. Your personal experiences, put together, gave me a panoramic view of the work that lies before us, and provided the foundation for improved services for your children.

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CHAPTER I

Introduction

The purpose of this project is two fold; (a) to examine population data for the NHJAX catchment area to determine the potential beneficiary population for the Children with Disabilities Coordinated Care (CDCC) program, and (b) to determine through a survey and existing database information, what specialized services the CDCC population requires. Important to the survey will be analysis of various factors which affect a families' perception and use of specialized care services. The results are tantamount to successful development of the CDCC program in Jacksonville.

The CDCC Program is a Department of Defense (DOD) initiative with two goals; (a) provide specialized medical services to military children with disabilities and (b) integrate the military treatment facility (MTF), the military and civilian community, and the family into a coordinated subsystem of care (CDCC Information Paper No. 2, 1992). Three military treatment facility (MTF) pilot sites were chosen by a DOD task force for this program; Madigan Army Medical Center in Washington, Evans Army Community Hospital in Colorado and Naval Hospital Jacksonville, FL (NHJAX).

Each site was chosen for different reasons, but together they allow DOD to receive a broad perspective of MTF requirements and capabilities in different parts of the country.

Jacksonville was chosen because of its heavy dependence on community resources for diagnosis and treatment of children with disabilities, and because Florida has a strong infants and children's medical program agency, the Children's Medical Services (CMS). Additionally, while internal resources at NHJAX are almost non existent with regards to diagnosing and treating children with special healthcare needs, Jacksonville is home to some of the finest civilian medical services in the country. In addition to hosting the largest contingent of military dependents in Florida as well as being the fourth largest catchment area for Navy Medicine in the United States (RAPS, 1992), Jacksonville is also a designated homesteading site for Navy members enrolled in the Exceptional Family Member (EFM) Program. This is a specially designed DOD program to match the special healthcare needs of family members with geographic locations that can meet the healthcare needs as well as the career needs of the active duty sponsor. Coupled together, the above facts will make the results of

implementing this program significant well beyond the Jacksonville area.

As with any new initiative, numerous problems must be properly identified and overcome to be successful. NHJAX began taking action on the CDCC program two years ago, soon after being identified as a pilot site. Discussions were held between representatives of NHJAX and CMS to define the objective and establish goals. Historical correspondence regarding these discussions indicates that CMS already had a developed patient care network, designed to coordinate and provide care for this specified population. This led to the determination that CMS should be the focal point of program development. Further initiatives in planning were directed towards this objective. A plethora of questions and action items centered on various elements of the program were developed, but little action taken.

No indication is given that the population to be served, or the community and medical services required were ever determined. Consequently, these two major issues still confront command personnel in their effort to develop the CDCC program. Without this information, it will be impossible for the CDCC task force to develop and implement an effective, efficient program which meets the basic needs of the beneficiary

population. The goal of this project then, is to establish through the use of an extensive survey questionnaire, exactly who is the beneficiary population and what services are needed in this program. The results will be a guide for the task force in laying the groundwork for program implementation.

The literature review clearly demonstrates that the benefits of early intervention in childhood disabling or developmental conditions, provides increased long term benefits to the child in adulthood and to society. Accordingly, the literature also demonstrates that correctly identifying the population to be served and the services needed, is essential to successful program implementation and maturity.

Conditions Which Prompted the Study

Once it was determined that CMS would be the focal point for providing services, they wanted to know how many people we expected to be in the program and what services would be needed. Compounding this issue was a general lack of knowledge about services and problems faced by families who were currently using special healthcare services, either on their own or through the EFM program. Since the CDCC project seeks to coordinate care for a subgroup of the EFM population,

it is absolutely essential that NHJAX gain a better understanding of needs and problems of this group. The EFM program database was the primary reference in determining this information.

Problem Statement

The problem is to determine, as accurately as possible, the potential beneficiary population for CDCC services and what type of specialized healthcare services the population needs.

Literature Review

The Education of the Handicapped Act (P.L. 94-142) provides for educational and medical services for children, ages 3 - 21, with disabilities (Healy, 1991). In 1986, amendments to this law expanded these services to children from 0 - 3 years of age (Healy, 1991; Cupoli, 1991). Cupoli (1991) goes on to indicate that this law was in response to research and experience which indicated that the deleterious effects of many handicapping conditions can be lessened through early intervention, specifically within the first 36 months of life.

In Florida, this legislative objective is vested in the Children's Medical Services (CMS), under the direction of the Department of Health and Rehabilitative Services (HRS) (Institute for Child

Health Policy (ICHP) publication, 1991-1992). The intent of the program, and one of CMS' guiding principles is to provide ". . . an accessible, comprehensive, family-centered, culturally competent, community based, and coordinated system of care for children with special health care needs (CSHCN) (ICHP Pub. 1991-1992, p. 5).

It is hard to doubt the benefits of early intervention services. Besides attenuation of some of the debilitating effects of handicapping conditions cited previously, Cupoli (1991) states ". . . for every dollar spent [by the state] in prevention and intervention we [the state] will save five to nine dollars in treatment services." (p. 286). This early intervention philosophy is also brought to the state level by Schulkind & Ausbon (1985) in describing the highly successful development of CMS in Florida. A fundamental philosophy in the early evolution of CMS was that investment of tax dollars on children's rehabilitation would save the state money in the future, by not having to provide for specialized care when the children became adults. An example of costs for children with disabilities is provided by Punch (1984), where she indicates that in 1984, the annual medical costs for a child afflicted with spina bifida

averaged \$100,000 for the first four years of life and upwards of \$250,000 over a lifetime. Newacheck (1990) reports that data is unavailable to accurately estimate the financial impact on families who have children with chronic disabling conditions. However, he does indicate that the annual "nondental medical charges" (p. 61) for disabled children, in 1989 dollars, averaged "\$1514 per disabled child and \$524 for each nondisabled child." (p. 61). Perhaps a greater measure of significance regarding knowing the population and services needed, is the distribution of expenditures for disabled care. In 1989 figures, ranked according to expenditures for the disabled population, the top ten percent of disabled children (charges in excess of \$4000) accumulated 65% of all charges. This group represented primarily inpatients, while the vast majority of disabled care is received in outpatient services (Newacheck, 1990). This fact can be of critical importance when trying to balance plans with actions. One recent study reported the results of early intervention in low birth weight, preterm infants at eight sites. Variables considered were maternal education, maternal age, ethnicity, initial health status, birth weight, and gender. Early intervention resulted in statistically significant improvement (P

<.01) in cognitive ability measured at age three, in children of mothers, both black and white, with a high school education or less (Brooks-Gunn, Gross, Kraemer, Spiker, & Shapiro, 1992). The authors surmise from this and other findings that biological and environmental factors play a part in intelligence development. Further, and important to this project, is their conclusion that "Such findings underscore the importance of providing services to young children and families tailored to the needs of individuals or subgroups of individuals." (Brooks-Gunn et. al, 1992, p. 1213-1214). Haber, (1991) reports on a Colorado study which showed that early intervention services allowed one third of the 1,300 identified handicapped children ". . . to begin school without additional help." (p. 132), another third needed some help and one third needed full time special education. Significant was the fact that nearly all children who were not identified early and did not receive early intervention services ". . . required extensive special education services." (p. 132).

Planning of services and financial considerations depend on knowing how many users are anticipated. According to Newacheck (1990), approximately 5% of the population below 18 suffer from a long term disability

or limitation caused by a chronic condition. This same group accounts for 31% of occupied bed days for the under 18 age cohort. For the under 18 population, disabled children have triple the admissions to hospitals as non-disabled children; the length of stay once hospitalized is twice as long (Newacheck, 1990). Dr. Newacheck goes on to say that "Overall, disabled children and youths use at least twice as many health services as nondisabled children."(p. 61).

CHAPTER II

Methods and Procedures

A catchment area population analysis and a catchment area telephone survey were conducted to determine the critical issues important to the CDCC task force.

Population Parameters

Population data from the Defense Medical Information System (DMIS) was used to determine the projected beneficiary population in the Jacksonville area. Of concern to this project are the age cohorts from 0 - 21 years of age. Even though the CDCC program was to initially target children ages 0 - 2, the services provided by CMS in Florida are extended to those up to age 21. Telephone conversations with the CDCC program manager at the Office of the Assistant Secretary of Defense for Health Affairs, (OASD(HA)) indicated that the age issue was not a concern to them. They want to see what kind of program Jacksonville can develop, so this is just another unique issue to this area.

Because the DMIS age cohorts are divided such that the last concerned cohort goes to age 24, adjustments were made to project the expected number of beneficiaries up to age 21. Table 1 shows the 1993

DMIS projected population figures by cohort with the adjusted figures to age 21.

AGE/SEX	DEP OF ACT.DUTY	DEP OF NG/RESERVE	DEP OF RETIRED	SURVIVOR	TOTALS
00 - 04/M	4,303	217	207	21	4,748
05 - 14/M	6,319	450	1,668	119	8,556
15 - 17/M	1,066	86	1,190	56	2,398
*18 - 21/M	415	41	913	46	1,415
00 - 04/F	4,107	220	193	14	4,534
05 - 14/F	6,164	402	1,634	102	8,302
15 - 17/F	1,140	92	1,125	44	2,401
*18 - 21/F	2,803	117	977	65	3,962
TOTALS	26,317	1,625	7,907	467	36,316

Table 1: 1993 population data by age cohort for NHJAX catchment area; * = cohort adjustment to age 21 from age 24 (adj. = total DMIS # in cohort, divided by # of cohort years (7), multiplied by cohort years up to 21 (4).)

Source: RAPS Population Projection Report - Nov 92

Appendix A provides projected population figures for years 1993 - 1996. This information should be valuable as a planning tool for program management. If the 5% figure cited above is applied to our population projections, we could initially expect over 1800 children to be eligible for services in the CDCC program. However, there are caveats to these projections which are explained more fully in Chapter IV.

Survey Questionnaire

A commercially developed survey questionnaire, prepared by Lewin ICF under contract with DOD, designed specifically to evaluate the CDCC program (see Appendix B) was used to collect the data. The survey consisted of 72 questions which generated over 200 variables for measurement. Permission to use the questionnaire was obtained verbally over the phone from Lewin ICF. The survey was comprehensive in nature and covered the following issues: (a) family demographics, (b) time frame issues (when diagnosed, care over time), (c) resources used (checklist provided), (d) current access to services (and difficulties), (e) knowledge of the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) Program for the Handicapped (PFTH), (f) EFM Program, (g) use of MTF services, (h) knowledge of changes in CHAMPUS or other programs, (i) school system, (j) parental involvement, (k) general satisfaction, and (l) their initial knowledge of the CDCC program.

Instructions for using the survey (intended as a phone survey) included notifying potential families via letter, prior to starting the survey. Appendix C is the Commanding Officer's letter sent to all survey respondents. The letter explains the purpose of the

survey, clearly indicates that confidentiality will be maintained, and that participation is not mandatory. When contacted, all respondents were again made aware of the confidentiality issue before questioning began. Validity and reliability of the instrument was assumed for two primary reasons; first it was developed by a firm that is in the business of developing and conducting such surveys, and second, it was extremely comprehensive. Each of the sections contained several questions related to the specific category. Taken as a whole, the categories combine to provide an extensive look at services, attitudes, perceptions and needs. For these reasons it is safe to assume that the survey results present a true picture of the special healthcare needs of this special population.

Printouts of the Jacksonville EFM database were obtained from the EFM program manager at the Bureau of Naval Personnel (BUPERS). The printouts were dated 31 Dec 92. It was from this database that all potential respondents were identified. The CMS system was not able to provide additional identification of children who may not be in the EFM program.

CHAPTER III

Results

Initial review of potential respondents from the EFM printouts identified 292 families with children meeting the age requirements for the CDCC program. From this, 277 letters were mailed, notifying them of the impending survey; addresses for the remaining families were not available through the hospital's Composite Health Care System (CHCS) database. It was from this identified population that the survey was conducted.

As reflected in survey question 67, the majority of the beneficiaries are very satisfied with the quality of care their children receive (74%). However, only 38% are very satisfied with their ability to access the needed services, 51% were just somewhat satisfied. The following results represent critical grassroots information necessary to begin development of policies and procedures for the CDCC program in Jacksonville. In those cases where total percentages for a response are greater than 100%, it can be assumed that the response categories were not mutually exclusive. Children with disabilities usually have a multiplicity of problems other than the diagnosed handicapping condition. For this reason, some of the

questions elicited responses which were not mutually exclusive of one another. A complete summary of results can be found in Appendix D.

The average age of the children was 8.5 years and 55% were males. Seventy-two percent were diagnosed with special healthcare needs between the ages of 0 - 4. Mothers were 73% of the respondents. The special needs of the children were primarily physical (70%) and learning disabilities (40%). Physical disabilities included everything from cerebral palsy to orthopedic problems to cancer. Learning disabilities covered retardation to attention deficit disorders. Ten families (16%) reported having more than one child with special needs, those needs evenly divided between physical (50%) and learning (50%). Ethnicity of the children was primarily white (82%) with 18% divided between black, hispanic, and other. Forty-six percent reported that both parents worked outside the home, either part-time or full-time. Related to this finding is that 92% reported that both parents live in the household.

Twenty-five percent of the families have lived in the Jacksonville area between one and two years, but 26% have lived here over five years. Thirty-five families reported having moved to Jacksonville after

their child was diagnosed as having special needs. Of those 35, 34% said it was easier to get services here compared to their last location while 37% said it was harder. The most commonly reported difficulty was getting information (44%) and trouble with the "system" (31%).

Civilian doctors provided the majority of initial diagnoses (60%) and most of the initial services were provided by civilian hospitals (45%). The next largest provider of initial services was specialty centers, which provided 29% of services. Specialty centers are defined as facilities, other than acute care in-patient facilities, designed to provide focused services. Such facilities are Nemours Childrens Clinic, Shriners Hospital, and specialized therapy centers. It was similar facilities in other locations that provided most of the initial services. CHAMPUS was the primary payer of initial services (60%) and other third party payers paid 24% of charges.

Services needed by the families were primarily therapeutic in nature. Speech/hearing was needed by 48% of respondents, special education was needed by 56% of respondents, 34% required physical therapy, and 30% required occupational therapy. The public schools are a major player in providing these services. Specialty

centers provide 28% of speech/hearing needs, schools, 69%. Special education is provided by specialty centers in 12% of cases, and 91% of this need is met by the public schools. Physical therapy is obtained from specialty centers in 38% of cases, while schools provide this service in 43% of the cases. Occupational therapy is received equally from specialty centers (50%) and schools (50%). Table 2 summarizes this important relationship, which will be discussed in the next chapter.

Service	Provider	
	Specialty Center	Public Schools
Speech/hearing	28%	69%
Special Education	12%	91%
Physical Therapy	38%	43%
Occupational Therapy	50%	50%

Table 2: Comparison of services provided by Specialty Centers and Public Schools for selected services

Complementing this finding is that CHAMPUS and the public schools were the two highest payers of these services, 66% and 49% respectively. Fifty-six percent responded that there was an overall plan for the services being provided, the majority of which were

designed by the school system as part of the individual education plan (IEP).

Obtaining current services was a frustrating experience for most respondents. Forty-eight percent said they had to do their own "leg work" in finding out what was available and how to gain entry into the system. This corresponds with data that indicates 30% of families learned of available services from special agencies, 38% by referral from the system (once in), and 23% by their own efforts. Respondents categorized their overall ability to access services as not very difficult (44%), difficult (26%), and easy (26%). When asked about difficulty in getting specific services (refer to question 27 and 38 of the survey), the overwhelming majority responded that it was not very difficult. When asked to compare their experiences in accessing care, with other military and civilian families who have children with disabilities, the results were very different. Table 3 shows this difference.

Question	More diffi cult	Same	Easier
#39. Your experience compared to other <u>military</u> families with disabled children?	3%	36%	52%
#40. Your experience compared to <u>civilian</u> families with disabled children?	26%	30%	31%

Table 3: Comparison of experiences with other military and civilian families who have disabled children

This question was somewhat difficult because most families said they didn't know any civilian families in their situations, and surprisingly, many didn't know other military families with disabled children either.

The Naval Hospital is essentially providing only primary care services to these families. Pediatrics provides 49%, family practice provides 10%, and the primary care clinic provides 5%. However, 48% felt that one provider at the hospital was most familiar with their child's care and treatment, although they spoke to this person infrequently (see question 53). This provider rendered mostly general care (66%) or follow-up for special situations (48%).

As noted earlier, current services provided by the public schools were significant. Sixty-two percent of the families reported receiving services from the

schools. Table 4 lists the four most significant services received.

Service	Percent receiving
Speech/hearing therapy	55%
Special Education	76%
Physical Therapy	32%
Occupational Therapy	32%

Table 4: Four highest services provided by public schools

Thirty-five families (57%) reported having a multidisciplinary care conference at some time in the past to discuss and develop treatment plans for their children. Those most frequently in attendance at such meetings were parents (97%), therapists (60%), and teacher/school officials (60%). All parents said that their concerns were treated seriously by the providers present at the conference; 77% of these parents were very involved in the discussion and decisions while 17% were only somewhat involved.

Overall, almost 90% were either very satisfied (38%) or somewhat satisfied (51%) with their ability to get the services needed. However, quality of care satisfaction was reversed; 74% were very satisfied with quality of care received and 23% were somewhat satisfied. When given the chance to state what problems they would most like to improve, 28% said better information, 23% wanted more services/assistance

within the MTF, 15% wanted CHAMPUS help, and 25% said other. "Other" refers to personal problems not reflected among respondents in general, ie. closer facilities, more school teachers, help with special equipment.

Finally, when asked about prior knowledge of the CDCC program, 7 families (11%) said they had heard of the program, all via contact with NHJAX personnel. Table 5 reflects the responses when asked how they hoped the program could help them.

Category	Percentage
Better/more information services	42%
Improved services (general)	35%
Provide more "in-house" (MTF) help	27%

Table 5: Help desired by respondents from the CDCC program

CHAPTER IV

Discussion and Conclusions

The medical assets in Jacksonville for patients with special healthcare needs, are some of the best and well known in the country. Tremendous opportunity exists for our beneficiaries to access outstanding specialized medical services, and for us to assist them in a unique way. We can relieve some of their frustration and anxiety over having to find out things for themselves, while building a reputation of community support to them and the Jacksonville medical and social services community. This conclusion is supported by the response to the question regarding comparison of their experience in getting special healthcare services, to other military families and civilian families who have children with special healthcare needs. Perception may be a factor since this question calls for a certain measure of speculation, but, only 3% thought their experience was more difficult than other military families. Conversely, 26% thought their experience was more difficult than a civilian family. This point presents a great marketing opportunity to improve the perception of our beneficiaries regarding how effectively and efficiently we meet their needs.

The population figures indicate a potentially substantial population of children with special healthcare needs in Jacksonville. Communications with local CMS officials indicate that approximately 12% of the local under 21 population have special healthcare needs. If the 5% figure cited earlier is used for comparison, we could expect from 1800 to over 4300 children between the ages of 0 - 21 years with special health care needs in our catchment area in 1993. Population projections for 1994 - 1996 show a slight decrease from 1993 in the population for Jacksonville. However, the potential number of CDCC eligible children remains from near 1780 to almost 4200, using the 5 and 12% figures. However, it should be pointed out that these estimates are based on a normally distributed population. While the city of Jacksonville can be considered to have a normally distributed population, the military community cannot. Because of the EFM program, Jacksonville is a homestead site for special needs families, thus we can expect a larger share of special needs children within our population. When our program is fully on-line this factor must be considered when discussing budgets, personnel, services, payments, etc.

The school system in Florida plays a larger role than first thought, in providing special healthcare needs to disabled children. Most parents seem happy to be getting the services through the school, but experienced differing degrees of difficulty with the school system in getting a child evaluated or reevaluated for services. A lot of this can perhaps be traced to the sources of funding. Using state dollars allocated to the schools, when federal dollars via CHAMPUS are available, is an unavoidable point of contention. However, the law regarding what schools must provide to this group of children is quite clear. Some parents stated that they had to remind school officials of the requirements of the law; subsequently they had no problems. Being the second largest payer of services after CHAMPUS makes the public school system a force to be included in our developmental decisions.

It would appear from the survey results that current families are getting the services they need. It is also apparent that they had little help from the military medical establishment in getting these services. CHAMPUS is the largest insurer and payer and the beneficiaries seem content to use it. However, most families would like to receive more from the

military hospital, as evidenced by their response to the last question of the survey. They want more information and services provided within the MTF. This desire certainly creates a ready market for the CDCC program.

Wanting more information and services from the MTF reflects a desire to make more and better informed choices regarding healthcare. Choice in healthcare decisions is a well known tenant of individual autonomy. It cannot be determined at this point what our beneficiaries' response may be if forced to choose/change a particular doctor or location to receive services, but history says this could affect their decision, and our program goals, to use inhouse services.

It was surprising to find that the CMS was not well known to the sample group. The CDCC task force has aligned itself closely with this organization, anticipating a synergistic working relationship. While many families had to use their own initiative and resources to eventually get services, very few of them knew about or contacted CMS. Had they known to contact CMS, many of them could not only have received help, but also would have been provided care coordination services to cover all of the child's needs. This

finding makes it all the more important to develop our relationship with CMS and use it to our advantage.

Several weaknesses of the study are noted. The survey instrument itself was not very "user friendly". Some of the questions seemed repetitive and others appeared to be in the wrong sections. The coding of responses and variables could have been better. The construction of the survey made it cumbersome to use. However, the survey will provide a sound basis for a follow-up survey in the future, once the CDCC program is on-line. Lastly, the survey exposed a weakness in our EFM tracking. With 16 letters returned because the family had moved and 34 phone numbers disconnected or changed, a problem exists with our mechanism to keep track of EFM families. This is not yet a task force issue but certainly one to be presented to the command for discussion. Our ability to track enrollment and disenrollment of families will be a major factor in the overall success or failure of the CDCC program.

CHAPTER V

Recommendations

The results of the survey were certainly enlightening. While the anecdotal comments provided by the respondents are not measured, they reflect a degree of frustration which is very telling. Also, time may have been a handicapping factor. None of the families had recently started dealing with the system, they had been using the system for special healthcare needs for some time. This may have clouded their perception of how hard or easy it may have been to initially obtain needed services, or what their perception of quality of care may have been. With these factors in mind, the survey points to several recommendations which are germane to the efforts of the CDCC task force.

The first recommendation is all encompassing. We need to develop a complete coordinated care program for this group of beneficiaries that includes enrollment, contractual arrangements with clinicians, and formal agreements with civilian healthcare organizations in order to provide care that is not available either through the schools or NHJAX.

Second, specific assets must be placed at NHJAX to conduct the CDCC program. The survey demonstrates the need for basic services. Formal requests should be

forwarded via the chain of command to acquire either military or civilian positions for a developmental pediatrician, nurse case manager(s), supporting health benefits advisors, and health care finders. If this program is to succeed, it cannot be fed the leftovers from the planning, programming, and budgeting table, it must be served a full helping of attention.

Third, we must focus the efforts of the eventual case manager for the program towards information collection and dissemination. This information should be heavily centered around the school system and the eventual contractual arrangements and agreements mentioned above. Even though the schools provide a large percentage of therapeutic services, parents commented that getting into the system was not always easy. Even parents who had Individual Education Plans (IEP) from other states were not able to transition into our public schools without problems. While our program will be a central point of contact for this population, a strong bond should be developed between our case manager, CMS, and school officials in order to facilitate these families getting the services needed through the schools. Since schools use state funding to provide these services, our program will have to develop a special understanding with the schools on how

state and federal funding will be utilized. Regarding IEP's; these address special educational needs which include medical needs. We must assist our families in developing an overall care plan that addresses medical needs which should complement the IEP.

A fourth recommendation concerns outside agencies. Several special organizations were repeatedly mentioned as being helpful in finding who, what, where, and how services were available. Our program must obtain basic information from entities such as Child-find, Easter Seals, Division of Blind Services, CMS and all other similar organizations in the city. This is again a point of contact issue; once we have this information and know how each system works, we will be able to better assist our beneficiaries in a more "hassle free" effective and efficient manner.

Short term day care was mentioned as being difficult for some families to find. An independent organization of military families has been organized at Naval Station Mayport to address this and other needs of families of children with special healthcare needs. A fifth recommendation is for our task force to open discussions with this group to combine information and assistance to other families. Some of these families would be excellent members of the task force for

showing us just what direction we should take on certain issues.

Since Jacksonville is a designated homesteading site for families with special healthcare needs, every effort should be made to develop a basic mail information packet for known prospective personnel being transferred to the area. Families would be directed to contact our case manager upon arrival to begin a smooth transition to services in Jacksonville.

Since therapeutic type services are the most needed services, we should develop a system that gets our beneficiaries into these services with minimal delay. The command should investigate possible partnership arrangements, personal services contracts, more active duty physical therapists, or other consulting arrangements which would bring this kind of service into our facility, on a regular and periodic basis. This would allow our special families to at least obtain easier evaluations or reevaluations. It would also provide a modicum of continuity of care for our providers, since we will be the "medical home" for these patients. The quality of care issue also becomes important to this recommendation. All though the majority of families say they are very satisfied with quality of care received, we have no way to monitor

this, especially in the schools. Another recommendation for our case manager is to visit some of the schools and their nurses, and make a determination as to the quality of services rendered. Such a determination will be useful in helping our special care needs children progress more fully in their therapy.

Attention must be given to CHAMPUS as the primary payer of services. Since this is the only health insurance of most of our families, the potential exists for us to negotiate payments for some of our most needed services and thus save our beneficiaries some money. It would also help reduce the overall CHAMPUS cost for this type of service in our area.

Last and perhaps most important is the recommendation that we engage in periodic open, formal discussions with these families. I was struck by their willingness to talk about their problems and experiences. They were excited that maybe someone was going to pay attention to this heretofore "disenfranchised" group of beneficiaries. We should develop something along the lines of a special healthcare consumers council forum to meet and discuss issues important to both sides. These people want to talk, and in the case of the group at Mayport they will

take action. This may be the most meaningful and beneficial thing we can do as the CDCC program takes form and comes to life.

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APPENDIX A

DEPENDENT CHILDREN POPULATION PROJECTIONS FOR THE JACKSONVILLE CATCHMENT AREA 1993 - 1996

1993 POPULATION PROJECTIONS JACKSONVILLE, FL				SOURCE: RAPS POPULATION PROJ. REPORT NOV 1992	
AGE/SEX	DEP. OF ACT. DUTY	DEP. OF NG/RES	DEP. OF RETIRED	SURVIVOR	TOTALS
0 - 4M	4,303	217	207	21	4,748
5 - 14M	6,319	450	1,668	119	8,556
15 - 17M	1,066	86	1,190	56	2,398
*18-21M	415	41	913	46	1,415
0 - 4F	4,107	220	193	14	4,534
5 - 14F	6,164	402	1,634	102	8,302
15 - 17F	1,140	92	1,125	44	2,401
*18-21F	2,803	117	977	65	3,962
TOTALS	26,317	1,625	7,907	467	36,316

Table A - 1: 1993 population projections for NHJAX

1994 POPULATION PROJECTIONS JACKSONVILLE, FL				SOURCE: RAPS POPULATION PROJ. REPORT NOV 1992	
AGE/SEX	DEP. OF ACT. DUTY	DEP. OF NG/RES	DEP. OF RETIRED	SURVIVOR	TOTALS
0 - 4M	4,198	213	205	21	4,637
5 - 14M	6,167	438	1,652	121	8,378
15 - 17M	1,040	84	1,178	56	2,358
*18-21M	406	40	902	46	1,394
0 - 4F	4,009	215	191	14	4,429
5 - 14F	6,015	393	1,619	102	8,129
15 - 17F	1,111	89	1,114	44	2,358
*18-21F	2,735	115	966	66	3,882
TOTALS	25,681	1,587	7,827	470	35,565

Table A - 2: 1994 population projections for NHJAX

1995 POPULATION PROJECTIONS JACKSONVILLE, FL				SOURCE: RAPS POPULATION PROJ. REPORT NOV 1992	
AGE/SEX	DEP OF ACT. DUTY	DEP OF NG/RES	DEP OF RETIRED	SURVIVOR	TOTALS
0 - 4M	4,130	210	205	21	4,566
5 - 14M	6,067	434	1,644	122	8,267
15 - 17M	1,023	82	1,170	58	2,333
*18 - 21M	399	39	894	47	1,379
0 - 4F	3,943	212	191	14	4,360
5 - 14F	5,917	389	1,610	104	8,020
15 - 17F	1,094	88	1,106	44	2,332
*18 - 21F	2,690	113	957	67	3,827
TOTALS	25,263	1,567	7,777	477	35,084

Table A - 3: 1995 population projections for NHJAX

1996 POPULATION PROJECTIONS JACKSONVILLE, FL				SOURCE: RAPS POPULATION PROJ. REPORT NOV 1992	
AGE/SEX	DEP OF ACT. DUTY	DEP OF NG/RES	DEP OF RETIRED	SURVIVOR	TOTALS
0 - 4M	4,085	207	205	21	4,518
5 - 14M	6,002	429	1,645	122	8,198
15 - 17M	1,012	82	1,169	58	2,321
*18 - 21M	395	39	890	47	13,719
0 - 4F	3,901	210	191	14	4,316
5 - 14F	5,854	384	1,612	104	7,954
15 - 17F	1,082	87	1,104	44	2,317
*18 - 21F	2,661	111	953	67	3,792
TOTALS	24,992	1,549	7,769	477	34,787

Table A - 4: 1996 population projections for NHJAX

APPENDIX B

CDCC SURVEY QUESTIONNAIRE

Start Interview

NOTE TO INTERVIEWER: BE SURE TO USE THE CHILD'S NAME OR RELATIONSHIP TO THE INTERVIEWEE IN PHRASING ALL QUESTIONS. THAT IS, DO NOT SAY, "HOW OLD IS YOUR DISABLED CHILD?" INSTEAD, WHENEVER POSSIBLE SAY, "HOW OLD IS JOHN?" OR "HOW OLD IS YOUR SON?"

I. We would like to begin by getting some background information on your family to help us evaluate our survey results. We may already have some of this information, but we just want to make sure it is all correct.

1) How old is [child's name]? _____

2) [Unless unclear, indicate child's sex here without asking]:

___ Male ___ Female

3) What is your relationship to [child's name]? _____

4) What are your son's/daughter's special needs? _____

5) How old was [child's name] when he/she was diagnosed? _____

6) How many parents live in the household? ___ One ___ Two

7) How many other children live in the household? What are their ages?

Number of other children ___

Ages _____

8) Have any of your other children been diagnosed as having special needs? If so, which children? What are their special needs?

- 9) What race or ethnicity best describes [child's name]? [If respondent objects to this question, explain that it could be important in evaluating whether children from all backgrounds are receiving equal treatment.]

White _____
Black _____
Hispanic _____
Other (specify) _____

- 10) What is your approximate annual family income? _____

- 11) What is the active duty parent's rank? _____

- 12) [If two parents living in household] Do both parents work outside the home? [If yes] Do both work full-time?

No _____
Yes, both PT _____
Yes, both FT _____
Yes, one PT and one FT _____

[If one parent living in household] Do you work outside the home? [If yes] Do you work full-time?

No _____
Yes, PT _____
Yes, FT _____

II. Location Issues:

- 13) How long have you lived at your current residence? _____

- 14) Where did you move from? _____

- 15) Was your move after [child's name] had been diagnosed as having special needs?

- 16) If you answered yes to the previous question, has it been easier, harder, or about the same getting services here compared to your previous location?

___ Easier ___ Harder ___ About the same

17) Why? What sort of problems did you encounter after moving here?

18) Does the child live in a location different from the sponsor's assignment? If so, why?

III. Time-frame Issues:

19) Who first diagnosed [child's name] as having special needs?

20) What services were initially provided immediately following that diagnosis?

21) How soon did they begin after the diagnosis? _____

22) Who provided them? _____

23) Who paid for them? _____

24) Has the way [child's name] has been cared for changed over time while you have lived here? If so, how?

25) Has it been easier, harder, or about the same arranging services for [child's name] ?
Why?

___ Easier ___ Harder ___ About the same

Reasons: _____

26) Have you had any help? If so, from whom? _____

IV. Types of Services/Programs:

- 27) What services does [child's name] receive? Who provides these services?
[Interviewer will read the following checklist]

<u>Service Received</u>	<u>Provider</u>
___ Speech/hearing_____	_____
___ Special education_____	_____
___ Physical therapy_____	_____
___ Occupational therapy_____	_____
___ Family visits, counseling, training_____	_____
___ Other psychological services_____	_____
___ Medical equipment_____	_____
___ Diagnostic medical services_____	_____
___ Other medical services_____	_____
___ Day care_____	_____
___ Respite care_____	_____
___ Transportation_____	_____
___ Case management or care coordination_____	_____
___ Other (specify):_____	_____

- 28) Who funds these services? Please list all payers you know of, such as your family, CHAMPUS, other insurance companies, the school system, other public agencies, etc.

- 29) Are there other services your child or your family needs that are not available? If so, what?

30) Has anyone in "the system" asked about your other needs? If so, who?

31) Do you feel there is an overall plan for the services provided to [child's name] ? If so, who designed it?

V. Current Access:

32) What did you have to do to get the services you do? Please discuss for each major type of service provided for [child's name].

33) What problems have you encountered? Please discuss for each major type of service provided for [child's name].

34) How did you learn what services were available?

35) What was the application process like?

36) Have you received any help in accessing these services? If so, from whom?

37 Overall, how would you characterize your ability to access the services available?

- ☐ Very difficult
- ☐ Difficult
- ☐ Not very difficult
- ☐ Easy

38) Please indicate the level of difficulty you have had accessing various services for your child or your family. [Interviewer will prompt respondent with each service listed in chart attached to back of survey.]

39) How do you think your experiences gaining access to services compare to those of other military parents of children with special needs?

- ☐ Your experience has probably been more difficult
- ☐ Your experience has probably been about the same
- ☐ Your experience has probably been easier

40) How do you think your experiences gaining access compare with non-military parents of children with special needs?

- ☐ Your experience has probably been more difficult
- ☐ Your experience has probably been about the same
- ☐ Your experience has probably been easier

41) If you have more than one child with special needs, what additional problems have you faced getting access to services?

VI. Program for the Handicapped (PFTH):

42) Are you familiar with CHAMPUS's Program for the Handicapped (PFTH)?

43) If so, was [child's name] enrolled? ☐

44) Is [child's name] enrolled now? ☐

45) How much trouble did you have applying for PFTH benefits?

- ☐ A lot
- ☐ Some
- ☐ Not much
- ☐ None

46) How much trouble have you had filing claims?

- ☐ A lot
- ☐ Some
- ☐ Not much
- ☐ None

47) What services have been funded through PFTH? _____

48) If your child has not been enrolled in PFTH, why not? _____

49) [Interviewer will ask if relevant, based on previous answers] Have you applied to PFTH and been rejected? If so, what was the reason for the rejection? Where were you living at that time?

VII. Services Provided by MTF:

50) What services are provided for your child by your Military Treatment Facility [Madigan, Fort Carson, or Jacksonville]?

51) Has the availability of any of these services changed over time? If so, please explain.

- 52) Is there one individual at the MTF who is most familiar with your child's condition and treatment? If so, is this individual a physician, a case coordinator, a Health Benefits Advisor, or someone else (please specify)?

53) How often do you talk to this person? _____

54) What types of assistance does this person provide? _____

VIII. Changes in CHAMPUS or Other Programs:

- 55) Have the services your child or family has received been affected by any changes in your health insurance? If so, how?

- 56) Have the services your child or family has received been affected by any changes in other programs available in your area? For example, did your child lose eligibility for a program, or did a program cut back on services it had provided? If so, please identify the program(s).

- 57) In general, has it become more or less difficult to get services for [child's name]? Please explain.

IX. School System:

- 58) What services have been provided for your child by the public school system?

59) What did you have to do to get those services? _____

X. Parental Involvement:

60) Has there ever been a multidisciplinary care conference organized to discuss various treatments for [child's name]? If you are not sure, was there ever a meeting involving more than one doctor, therapist, teacher, other school officials, or others caring for your child?

___ Yes ___ No

If so, who attended? Were you invited to participate in the meeting? Where was the meeting held? Do you remember when this meeting took place, approximately?

61) If you attended such a conference, how would you describe your participation in the discussion and decisions?

- ___ Very involved
- ___ Somewhat involved
- ___ A little involved
- ___ Not involved at all

62) Do you believe your concerns were treated seriously by the various providers?

63) Who do you think has the most influence on what care [child's name] should receive?

- ___ You (and/or your spouse)
- ___ Doctors
- ___ Teachers/school officials
- ___ CHAMPUS
- ___ Another health insurer
- ___ Other(specify): _____

- 64) How often would you say you or your spouse meet with doctors, teachers, or other providers caring for [child's name]?

- 65) In general, are you satisfied that you have had enough control over the services provided to [child's name]?

XI. General satisfaction:

- 66) Overall, how satisfied are you with your ability to get the services that [child's name] needs?

☐ Very satisfied
☐ Somewhat satisfied
☐ Somewhat dissatisfied
☐ Very dissatisfied

- 67) Overall, for those services you were able to arrange, how satisfied have you been with the quality of care [child's name] has received?

☐ Very satisfied
☐ Somewhat satisfied
☐ Somewhat dissatisfied
☐ Very dissatisfied

- 68) What problems would you most like to improve concerning care for your child's needs?

XII. Initial knowledge of CDCC:

- 69) Prior to receiving notice about this interview, had you heard anything about a new military plan for coordinating care for disabled children?

70) If so, how did you hear about the plan? _____

71) What do you know about it? _____

72) How do you hope such a plan could help you? _____

Thank you very much for taking the time to participate in this survey. Your answers will be very helpful in trying to improve the CDCC program.

SECTION V, QUESTION 38: SUMMARY OF ACCESS TO SERVICES FOR YOUR CHILD

(Please Check One Box for Each Service Listed)

Getting This Service for My Child Has Been:

Type of Service	Very Difficult	Somewhat Difficult	Not Difficult	Service Not Needed	Comments
Speech/Hearing					
Special Education					
Physical Therapy					
Occupational Therapy					
Family Visits/ Counseling/Training					
Psychological Services					
Medical Equipment					
Diagnostic Medical Services					
Other Health Services					
Day Care					
Transportation					
Case Management					
Other (Specify)					

APPENDIX C

CDCC Pre-Survey Letter

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Dear Beneficiary:

I am writing to ask for your support in development of a new project being implemented at our facility. The principle objective of the Children with Disabilities Coordinated Care Program (CDCCP) is to make it easier for military parents of young children with special healthcare needs to arrange for necessary services to be provided for their children.

I am very excited about the opportunity that this project affords to you and other special beneficiaries of this region. In order for us to design and implement this new project most effectively, it is very important that we hear directly from you - the parents who have already been trying to get access to services and funding. Therefore, we will be conducting a telephone survey of families having children with special healthcare needs. We are sincerely interested in hearing of your success and/or failures in trying to obtain special services for your children. Our aim is to learn from you so that we can, in turn, provide better healthcare delivery for your children.

Your family is one of those that was selected at random from a pool of families enrolled in the Exceptional Family Member Program in Jacksonville. You are not obligated in any way to participate in this survey but your cooperation will be very important in helping us to implement the CDCCP most effectively. A better CDCCP, in turn, will ultimately mean improved delivery of services for all military children with special needs, in terms of access, quality of care, and possibly lower costs to you. Therefore I strongly urge you to take the time to participate when you receive a telephone call in a couple of weeks from my project officer who will be conducting the survey.

Please accept my assurances that all information gathered during the survey will remain strictly confidential. It is very important to us that you answer all questions as candidly as possible, whether your responses are negative or positive.

Thank you very much for helping us help you.

Sincerely,

N. K. DYSART
Captain, Medical Corps
United States Navy
Commanding Officer

APPENDIX D

CDCC Survey Questionnaire Results

The population data for the survey was obtained from the Naval Military Personnel Data System (NMPDS) database, from the Bureau of Naval Personnel (BUPERS). It consisted of three printouts of the known families enrolled in the EFM program in the Jacksonville area, which was divided into three separate demographics, NAS Jacksonville, NAS Cecil Field, and Naval Station Mayport. The printouts were dated 31 Dec 92. Eligibility for the CDCC program was determined by reviewing the birth date of all enrolled EFM's. To be eligible for the CDCC program in Jacksonville, a child must be 21 or younger. Consequently, anyone with a birth year of 1973 or later was deemed eligible for CDCC. This means they would be eligible for services under the CDCC program through 1994, giving NHJAX time to establish the program in 1993. Two-hundred ninety two (292) families were identified as having children in the CDCC category; a total of 314 children were represented by these 292 families. Since the survey questionnaire included questions about multiple disabled children in a family, only one questionnaire per family was completed.

An explanation letter about the survey was sent from the Commanding Officer of Naval Hospital Jacksonville, to 277 of the 292 families identified. This was because addresses could not be found for the other 15 families. The letter explained the purpose of the survey and informed each recipient to expect a call from the CDCC project officer. Confidentiality and the freedom of choice in participation were also stressed in the letter. The letters were mailed two weeks before the survey began. This was done to allow for return of letters that may be undeliverable due to moves, address changes, etc. and thus have a more accurate population to survey.

The CDCC survey questionnaire consisted of 72 questions divided into 12 sections. The questionnaire was designed as a telephone survey. It was developed by a civilian firm under contract with the Department of Defense (DOD) to develop baseline CDCC information at the three pilot sites. It was administered to sixty-one ($n = 61$) individuals. This represented 21% of the 292 identified families with children under the age of 21 in Jacksonville. However, due to some letters being returned as undeliverable (16), phone numbers being either incorrect, disconnected, or not in service (34), and ten (10) families either choosing not

to participate or no longer in the EFM program, 60 potential participants were discounted from the original population. Thus, the population was adjusted to $N = 214$ vice 292. The actual survey sample then represented 29% of the eligible population.

The issue of randomness was addressed by going through each list in order. Names on each list were in ascending order of the sponsors social security number. Calls were made in succession, without regard to getting an answer. If a number was busy, the next number was dialed. The survey was conducted over a 30 day period and was terminated based on date and having surveyed at least 20% of the known population. Each list was sampled based on their contribution to the total unadjusted population. NAS Jacksonville represented 36% of total EFM families, Naval Station Mayport 47%, and NAS Cecil Field had 17%. At a minimum, the same percentage of samples were obtained from each list. Table D - 1 summarizes the survey preparation and adjustment figures.

SITE	CDCC FAMILIES % of total	CDCC ELIGIBLE (# children)	TOTAL LETTERS SENT	ADJUSTED POPULATION (number of families) (N)	FAMILIES SURVEYED (n) % of adj. pop. by area
JAX	106/36%	114	99	83	29/35%
MAYPORT	138/47%	151	129	89	22/64%
CECIL	48/17%	49	48	42	10/24%
TOTALS	292	314	277	214	61/29%

Table D - 1: Summary of survey preparation and sample population adjustments

Survey Results and Analysis

The 72 questions of the survey were divided into 12 sections as follows: (I) demographic data, (II) location issues, (III) time-frame issues, (IV) types of services/programs, (V) current access, (VI) Program for the Handicapped (PFTH), (VII) services provided by MTF, (VIII) changes in CHAMPUS or other programs, (IX) school system, (X) parental involvement, (XI) general satisfaction, and (XII) initial knowledge of CDCC. Most results were tabulated using a "one-zero" coding, creating dichotomous data for a majority of all answers. The averages and standard deviations for each variable were then computed by counting all responses coded as a "one". Some responses were categorized by the surveyor; in such instances, this is noted.

The results of each question, by section, follows in

Table D - 2.

Question	Average	Comments
<u>Section I.</u>	8.5 years	
1. Child's age?		
2. Child's gender?	55% males; 45% females	
3. Parent giving survey info?	73% - mothers	
4. What are the special needs?	70% - physical 3% - emotional 40% - learning disabilities	Categories were arbitrarily established by surveyor; total % is above 100 due to some children having needs in multiple categories
5. Child's age at Dx?	5% - invitro 72% - 0 - 4 21% - 5 - 14 2% - 15 - 17 0% - 18 - 21	Age cohorts were established to match the cohorts of the RAPS population data
6. Number of parents in the household?	92% reported both parents living in the home	
7. Number of other children living in the home?	51 families responded as having other children at home: avg. was 1.25 children per home	Accounted for 76 additional children; for the next question, n = 76.
7a. Ages of other children?	17% 0 - 4 67% 5 - 14 8% 15 - 17 5% 18 - 21	
8. Other children diagnosed w/ special needs?	10 of 51 families reported "yes": 20%	

8a. Which ones?	8% 0 - 4 75% 5 - 14 8% 15 - 17 8% 18 - 21	12 children were reported; n = 12 for this question; 2 children were over 21
8b. What are their special needs?	50% - physical 0% - emotional 50% - learning disabilities:	
9. Ethnicity of child?	82% White 8% Black 5% Hispanic 5% other	
10. Approx. annual family income?	2% \$15K or less 15% 16 - 20K 34% 21 - 25K 15% 26 - 30K 11% 31 - 40K 18% 41 - 50K 5% 51K or above	Income categories arbitrarily assigned
11. ACDU parent rank	0% - E1 - E3 8% - E4 18% - E5 38% - E6 11% - E7 7% - E8 2% - E9 <hr/> 0% - O1 0% - O2 7% - O3 5% - O4 3% - O5 0% - O6	One respondent was retired; categorization was done by surveyor
12. Both parents work outside home?	54% - No 30% - both full-time 16% - one part-time, one full-time	It was assumed that the ACDU was full-time, whether one or two parents lived in the home
<hr/>		
<u>Section II</u> 13. How long lived at current residence?	15% - less than a year 25% - 1 - 2 years 11% - 3 - 4 years 26% - over 5 years	

14. Where did you move from?	58 different locations were reported from all over the world; California and Norfolk, VA were the most frequently reported; 10 from CA, 9 from Norfolk	
15. Was move after Dx?	57% - Yes	35 families; n = 35 for the next question
16. Getting services here compared to previous location?	34% - easier 37% - harder 23% - same	n = 35
17. Problems after moving here?	13% - diff. w/ school system 44% - diff. getting info 31% - diff. w/ system 13% - diff. getting personal help	Categories assigned by surveyor based on responses; n = 16
18. Child live apart from sponsor assignment?	97% - no	only 2 lived apart, one in residential care fac., one for personal hardship
<hr/>		
<u>Section III</u>	60% - civ. MD	categories assigned by surveyor
19. Who first diagnosed?	41% - military MD	
20. What services provided immed. following dx?	15% - specialty referrals 11% - surgery 26% - therapy 8% - counselling 8% - special meds 28% - special testing 8% - special school	categories assigned based on responses; some families had responses in multiple categories Only 55 families required these services; n = 55 for next question
21. How soon were services provided?	45% - within 2 weeks 33% - 2 wks - 1 month 22% - over one month	6 families reported not needing immediate services

22. Who provided the services?	27% - military hosp.	specialty centers are defined as Nemours, Shriners, Easter Seals, etc.
	45% - civ. hospital	
	29% - specialty center	
	9% - schools	
23. Who paid for the services?	5% - self paid	percentages are greater than 100% due to multiple payor for some families; other TPP are CMS, Easter Seals, Shriners; schools reflect state funding; gov't. refers to care received in MTF
	60% - CHAMPUS	
	24% - other third party payers	
	4% - schools	
	35% - government	
24. Care changed over time while living here?	49% - yes	most responses indicated that as child got older and parents gained familiarity w/ system, things became easier
25. Easier, harder, same in arranging services?	36% - easier	
	28% - harder	
	34% - same	
26. Any help from anyone in getting services?	54% - yes	referrals from NH; help from Nemours, Child-find, family & friends

Section IV.

See Table D - 3

27. What services does child receive?

28. Who funds these services?	18% - self paid
	66% - CHAMPUS
	19% - other TPP
	49% - schools
	11% - government

29. Are any needed services not available?	33% - yes	most commonly expressed needs were financial help, day care for handicapped kids, respite care for parents, and equipment needs
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30. Has the "system" asked about these other needs?	8% - yes
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31. Is there an overall plan for services provided to child?	56% - yes	the public school system through the IEP's were the most common "designers" of plans
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<u>Section V.</u> 32. What did you have to do to get current services?	38% - referrals 48% - own initiative 18% - agency help 21% - schools	referrals from either civ. or MTF; own initiative was making calls and asking questions without help; agencies were Nemours, Child-find, Easter Seals, Shriners, etc; some required multiple assistance
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33. What problems have you encountered?	33% - trouble w/ system 11% - CHAMPUS/ insurance 7% - equipment 21% - personal help 7% - financial	categories arbitrarily assigned based on responses; system means probs. w/ access, referrals, etc.
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34. How did you learn what services were available?	30% - special agencies 21% - family/ friends 23% - own initiative 38% - referral from system 7% - schools	categories arbitrarily assigned based on responses;
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35. What was application process like?	71% - easy 32% - hard 39% - long & involved 64% - short & simple	only 29 families reported having any kind of application process for services; n = 29 for this question
36. Received any help getting current services?	38% - yes	
37. Overall ability to access avail. services?	8% - very difficult 26% - difficult 44% - not very difficult 26% - easy	
38. Level of difficulty accessing various services?	See Table D - 4	
39. Your experience gaining access compared to other military families with disabled children?	3% - more difficult 36% - same 52% - easier	
40. Your experience gaining access compared to <u>civilian families</u> with disabled children?	26% - more difficult 30% - same 31% - easier	
41. More than one child w/ special needs, what other problems have you had?		only one family responded, had problems getting school to provide services
<hr/>		
<u>Section VI.</u>	41% - yes	only 25 families reported being familiar w/ this program; n = 25 for the next two questions
42. Familiar with CHAMPUS Program for the Handicapped (CPFTH)?		
43. Was child enrolled?	60% - yes	n = 25; 15 families said yes

44. Is child now enrolled?	52% - yes	n = 25; 13 families said yes
45. Trouble applying for CPFTH benefits?	20% - a lot 13% - some 7% - not much 60% - none	questionnaire did not allow for determining what kind of trouble; n = 15
46. Trouble filing claims under CPFTH?	20% - a lot 7% - some 13% - not much 53% - none	n = 15
47. What services have been funded under CPFTH?		multiple services funded for several families; speech, PT/OT & other therapies; equipment; Nemours care; CPFTH needs to be better understood by staff and families
48. If child never enrolled, why not?	56% - not familiar w/ program 10% - didn't qualify	CPFTH is very specific in benefits authorized; several families hadn't asked and HBA about the program, they decided themselves that child didn't qualify
49. Ever applied for CPFTH and been rejected?	100% - no	

<u>Section VII.</u>	49% - Pri. Care -	Categories arbitrarily assigned according to responses;
50. What services are provided for child by MTF?	PEDS	
	10% - Pri. Care -	
	FPC	
	5% - Pri. Care -	
	PCC	
	21% - Pharmacy	
	11% - Ancillary	
	23% - Other	

51. Availability of these services changed over time?	26% - yes	better due to familiarity w/ system;
52. Is one individual at MTF most familiar w/ care & treatment?	48% - yes	29 of 61 responded yes; n = 29 for next two questions
53. How often do you talk w/ this person?	3% - weekly 21% - monthly 14% - 2-3 x/month 0% - every other month 31% - quarterly 31% - other	n = 29
54. What types of assistance does this person provide?	66% - general care 48% - follow up 10% - prescriptions 10% - other	n = 29; avg. is over 100% due to multiple services/family
<hr/>		
<u>Section VIII.</u>	15% - yes	
55. Have services child rec'd. been affected by changes in health insurance?		
56. Have services child rec'd. been affected by changes by other programs in the area?	10% - yes	
ADDED QUESTION Is CHAMPUS your only health insurance?	92% - yes	only five families had other health insurance; several had CHAMPUS supplements, but this was counted as CHAMPUS
57. Has it become more or less difficult to get services?	19% - more 52% - less 28% - same*	* this response was added because of the number of responses (17/61)

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<u>Section IX.</u>		
58. What services provided for child by public schools?	55% - speech/hearing therapy 76% - spec. educ. 32% - phys. therapy 32% - occup. therapy 5% - counselling 21% - transport. 26% - other	38/61 families reported receiving services from public schools; n = 38; categories assigned according responses and categories from question #27;
59. What did you have to do to get school services?	28% - personal initiative 50% - help from outside agencies	n = 38; outside agencies such as Child-find, Nemours, & HRS divisions were prominent
<hr/>		
<u>Section X.</u>		
60. Ever been a multidisciplinary care conference to discuss care & treatment?	57% - yes	35/61 families reported having such a conference; n = 35 for the next three questions
60a. Who attended this conference?	97% - parents 43% - doctors 60% - therapists 29% - counsellors 60% - teachers/school officials 9% - nurses	categories assigned by surveyor based on responses; nurses were home care, case coordinators; n = 35
61. How would you describe your participation in the discussion/decisions?	77% - very involved 17% - somewhat involved 3% - little involved 3% - not involved	n = 35
62. Were your concerns treated seriously?	100% - yes	n = 35
63. Who do you think has the most influence on what care child should receive?	77% - you/spouse 11% - doctors 8% - teachers/school 3% - CHAMPUS	

64. How often you or spouse meet w/ doctors, teachers or other providers?	8% - weekly	"other" covered anything from never, to twice yearly to as needed
	23% - monthly	
	11% - 2-3 x/mo.	
	2% - every other month	
	31% - quarterly	
	23% - other	

65. In general, are you satisfied with your control over services provided?	92% - yes
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Section XI.

66. Overall, how satisfied with ability to get services needed?	38% - very satisfied
	51% - somewhat satisfied
	11% - somewhat dissatisfied
	0% - very dissatisfied

67. Overall, for services rec'd., how satisfied are you with quality of care?	74% - very satisfied
	23% - somewhat satisfied
	3% - somewhat dissatisfied
	0% - very dissatisfied

68. What problems would you most like to improve?	23% - more services & assistance in MTF	categories assigned by surveyor based on responses; "other" covers personal type responses such as more school teachers, equip. help, closer facilities
	15% - help with CHAMPUS probs.	
	28% - better information services	
	25% - other	

Section XII.

69. Prior to this, had you ever heard of CDCC?	11% - yes	7/61 families had heard of CDCC; n = 7 for next two questions
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70. How did you hear about it?	all heard through contact with NHJAX personnel
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71. What do you know about it? Nothing specific, only that it is supposed to help access to services

72. How do you hope such a plan could help you? 27% - provide "in-house" (MTF) help
42% - information services
35% - improved services

categories assigned by surveyor based on responses; n = 48

Table D - 2: Summarized results to CDCC Survey (except #27 & #38)

Question 27: What services does the child receive? Who provides?
(n = 61) for "Service" and "Average". For "provider" n equals the number of respondents for that service.

Service	Avg.	Provider				
		Private	NH	Civ Hosp	Spec Center	Schools
Speech/hearing	48% 29/61	10% 3/29	3% 1/29	3% 1/29	28% 8/29	69% 20/29
Special Educ.	56% 34/61	3% 1/34			12% 4/34	91% 31/34
Phys. therapy	34% 21/61	24% 5/21			38% 8/21	43% 9/21
Occup. Therapy	30% 18/61	17% 3/18			50% 9/18	50% 9/18
Family visits, counselling, training	23% 14/61	36% 5/14	7% 1/14	7% 1/14	36% 5/14	14% 2/14
Other psychol. services	16% 10/61	80% 8/10			30% 3/10	
Medical equip	30% 18/61	56% 10/18	11% 2/18		28% 5/18	
Diagnostic medical services	23% 14/61	36% 4/14	29% 4/14	21% 3/14	21% 3/14	

Other medical services	34% 21/61	29% 6/21	38% 8/21	9% 2/21	38% 8/21	
Day care	23% 14/61	36% 5/14			14% 3/14	7% 1/14
Respite care	7% 4/61	75% 3/4			25% 1/4	
Transportation	25% 15/61	7% 1/15			7% 1/15	87% 13/15
Case mgt/ Care coord. services	20% 12/61	17% 2/12	8% 1/12		83% 10/12	

Table D - 3: Summarized results to question 27

NOTE: Percentages may not equal 100% since several families reported more than one provider of a service. Others reported payers of service, rather than who was providing it.

Question 38: Difficulty in getting the above services. (n = 61)

Type of service	Very Difficult		Somewhat Difficult		Not difficult	
Speech/hearing	7%	2/29	21%	6/29	76%	22/29
Spec. Educ.	6%	2/34	32%	11/34	62%	21/34
Phys. Therapy	5%	1/21	10%	2/21	86%	18/21
Occup. Therapy	6%	1/18			94%	17/18
Family visits, counselling, training	7%	1/14			93%	13/14
Other psychol. services	10%	1/10	10%	1/10	80%	8/10
Medical equip.	6%	1/18	6%	1/18	89%	16/18
Diagnostic medical services			29%	4/14	71%	10/14
Other medical services			29%	6/21	71%	15/21
Day Care	21%	3/14	21%	3/14	57%	8/14
Transportation					100%	15/15
Case management			8%	1/12	92%	11/12

Table D - 4: Summarized results to question 38